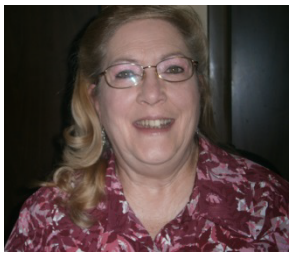
Hopes and Dreams

Huntington's Disease Society of America - Illinois Chapter Quarterly Newsletter

Huntington's Disease Society of America
Illinois CHAPTER

President's Message



Dear Illinois Families,

Wow!! We are off to an exciting start this year. In January we had our annual Dinner Dance, themed, "Score 4 HD". The dinner dance was a huge success and a great time was had by one and all. Kudos to Barry and Marilyn Kahn and their team for organizing this event.

That was followed by a great state conference in February titled "*Empowerment for Managing HD*." Our state conference was held at Northwestern Memorial Hospital this year and we had a great turnout once again. Kudos to Emily Zivin and Holly Fraleigh and their team for a job well done.

Great things continue to happen…Dr. Danny Bega and his staff at Northwestern Memorial Hospital have been named as an HDSA Center of Excellence. Congratulations! This will help us to reach many more families with the special services they need. Illinois now has two Centers of Excellence to serve the HD families of Illinois.

May is Huntington's Disease Awareness month. We are already reaching out to businesses and corporations in Chicago and asking them to turn their lights BLUE for HD Awareness. We will also be celebrating the 13th Annual Team Hope Walk at the Naperville Riverwalk on May 21.

June brings the HDSA National Convention to Schaumburg!! Mark your calendars for June 22 - June 24. For more information about the National Convention go to: **http://www.hdsa.org/convention**

Be sure and check out the information for scholarships for Illinois residents, and you can also book your room at the above link. While at the convention, be sure to stop by the Illinois Chapter table and say hello and purchase your convention T-Shirt! We look forward to seeing you there.

We are still in the planning stages for the rest of the year. Why don't you think about joining us? We are always looking for fresh ideas!

See you soon,

Susie Hodgson
President, HDSA Illinois Chapter
(**Illinois@hdsavolunteer.org)**

WE ♥ VOLUNTEERS

Family is *everything*

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This newsletter attempts to report items of interest relating to the individuals with Huntington's Disease, their families, healthcare professionals, and interested friends and supporters. HDSA and the Illinois Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Illinois Chapter.

Introducing New HD Mobile App

The HDNavigator mobile app, created by the Huntington's Disease Society of America, is a collection of tools and resources for all members of the HD Community – patients, caregivers, at-risk individuals, as well as family members and friends. The app was made possible by a generous gift from Lundbeck Pharmaceuticals.

HDNavigator features:

- Vital information for emergencies, including talking points and emergency contacts
- Medication and general life reminders perfect for both patients and caregivers
- A contacts and notes section for organizing information from appointments
- Communication boards to help those who have trouble speaking
- A peer connector to find nearby HDSA Chapter members or National Youth Alliance members
- A mobile "locate resources" feature to find your closest HDSA Center of Excellence, Social Worker, Support Group or other resources
- An up-to-date event finder to help get involved in your community and meet others to make a difference
- A listing of important related links and suggested apps and games for HD families.

If you are searching for the app in either ITunes or Google play please search "HDNavigator".

Download on iTunes

GET IT ON Google play

Lake County HD Support Group Change of Date

The April, 2017 Lake County support group will meet on the third Monday, April 17, instead of the regularly scheduled second Monday.

The May meeting will be on the regular scheduled date of May 8. Any questions, please contact Marilyn Kahn at 847-204-2403.

HD Community Service

by Marilyn & Barry Kahn

In the picture left to right: Susan Jacobi (Emil Kurinsky's sister), Emil Kurinsky, Tim Carrasca, and seated is Amanda Carrasca

The Thomas Cellini Huntington's Foundation's 12th annual Spring Fling was held on Saturday, March 18 at Idlewild Country Club in Flossmoor.

As a result of many people's efforts, a well-deserved Huntington's family received a fully converted van donated from an HD family to an HD family!

The van was donated in a presentation at Saturday's event attended by both parties. Emil Kurinsky, whose wife, Carole, passed away from Huntington's disease, requested as her last wishes to give the van to a family in the HD community. Emil presented the van to the family of Tim and Amanda Carrasca. Everyone in attendance was deeply touched by the act of kindness and generosity.

Our thanks go out to Emil for his generosity and to Barbara Cellini and her foundation for making this happen.

About the Northwestern HD Clinic, an HDSA Center of Excellence

Submitted by: Danny Bega, MD, MSCI
Assistant Professor, Dept. of Neurology, Division of Movement Disorders
Associate Director, Neurology Residency Program
Northwestern University Feinberg School of Medicine

The Northwestern Huntington's disease clinic is a part of the Northwestern University Parkinson's Disease & Movement Disorders Center. It is located in the heart of downtown Chicago. Our mission is to improve the quality of care for patients with HD, advance knowledge about the disease, and provide support for those dealing with the disease as well as their families. We achieve this through work in the clinic, the community, and the laboratory.

- Our clinic offers comprehensive care and management of HD including neuropsychiatric care and genetic counseling. Our comprehensive approach to the diagnosis and treatment of the disease is achieved with the collaboration of experts in the fields of neurology, psychiatry, nursing, genetics counseling, social work, rehabilitation services, and more. Our clinics meet on Fridays and appointments can be arranged by calling 312-695-7950 or emailing HD@nm.org**.** We are located at 675 N. Saint Clair, Chicago, IL. 60611.
- Our community outreach includes teaming with our local HDSA chapter to develop a **support group for "at-risk" and presymptomatic individuals** with HD. We also put on an annual patient and family educational symposium. This year the symposium will take place on **November 11, 2017** at our downtown campus.
- Finally, as a Huntington Study Group (HSG) certified research site we are dedicated to advancing clinical and translational research in HD through participation in trials. Our basic scientists, including the Chairman of our department, are also extensively involved in HD research.

Chicago Area Centers of Excellence

HDSA Center of Excellence at Rush University Medical Center
1725 W. Harrison St., Ste. 755, Chicago, IL 60612
Director: Jennifer G. Goldman, M.D., M.S.
Associate Professor, Section of Parkinson Disease and Movement Disorders, Department of Neurological Sciences
Rush University Medical Center
1725 W. Harrison St., Suite 755, Chicago, IL 60612
Office: (312-563-2900) ~ Fax: (312)-563-2024

CONTACT:
Kim Janko, RN - HD Clinic Nurse 312 563-2030 or 312-942-5003 (kimberly_janko@rush.edu)
Sarah Mitchell, MSW, LCSW - Clinical Social Worker, Health and Aging (sarah_mitchell@rush.edu)
Research Coordinator: Courtney Timms, BS Research coordinator 312-563-2698 / Fax: 312-563-2684 (courtney_Timms@rush.edu)

HDSA Center of Excellence at Northwestern Medicine Galter Pavilion (at Northwestern Memorial Hospital)
675 North Saint Clair, Suite: 20-100, Chicago, Illinois 60611
Danny Bega MD, MSCI - Assistant Professor, Dept. of Neurology, Division of Movement Disorders
Main Number: (312) 695-7950 ~ Fax: (312) 695-5747
Making an appointment: Our clinics meet on Friday mornings
To make an appointment, please contact our nurse coordinator Mickey Domiano at (312) 695-7950

CONTACT:
Social Worker: Pamela Palmentera, LCSW, (312) 503-4397
Genetics Counselor: Lisa Kinsley, CGC, (312) 503-0154
Research Coordinator: Karen Williams, CCRP, (312) 503-5645
http://huntingtons.nm.org

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Speech and swallowing problems in Huntington's disease

How is speech affected in HD?
Speech and swallowing problems are common in Huntington's disease (HD). To speak, we need to use more than 100 muscles in our body! These include muscles for breathing and muscles in our voice box (larynx), palate, face, mouth, tongue and jaw.

Involuntary movements in HD can interrupt speech. Breath is the power to one's voice, and speech is like gas to a car. When sudden involuntary or jerking movements occur in the trunk and neck, ones breathing can be affected. One's voice can be "cut off" or interrupted. As a result, the voice becomes intermittent, goes in and out, and sounds softer. When involuntary movements occur in the face, jaw, soft palate, and tongue area, speech sounds are either distorted or not produced. All of this can make one's speech hard to understand. This can affect one's ability to communicate wants and needs, relationships with loved ones, and participation in social life and medical care.

Can speech problems be treated in HD?
Yes. Speech evaluations in HD, especially early on, can introduce patients and families to various ways to adapt to changes in speech, improve their speech intelligibility, and learn effective ways to communicate. In more advanced HD, assistive and augmentative devices or smart phone applications can be helpful.

How is swallowing affected in HD?
Dysphagia is a technical term for swallowing difficulty, i.e., when one has trouble moving food from the mouth into the stomach. Dysphagia can occur in HD, especially as it advances, and can have thinking and motor components. For example, the consistency of foods and drinks, size of bites or sips, and pace of eating are choices one makes and can affect swallowing. If food is held in one's mouth too long, then there can be too much food to swallow safely. Dysphagia can present as choking on liquids, coughing on foods, and chewing (mastication) difficulties. It can lead to inadequate caloric intake, malnutrition, and weight loss. Sometimes it can lead to aspiration (the entry of food or drink into the voice box and lungs, rather than going into the stomach), which can lead to pneumonia and respiratory complications.

Warning signs of dysphagia in HD:
Decreased alertness or cognitive problems
1. Playing with food
2. Taking inappropriate size of bites (too large)
3. Talking during attempts of swallowing
4. Keeping food in the mouth without chewing or swallowing
Changes in food preference and eating habits
1. Avoiding eating in front of others or foods of specific consistency, e.g., breads or crackers
2. Taking longer time to eat a meal
3. Tongue pushing food or drink out
4. Needing to take liquid frequently (e.g., every bit to "wash down" food) or to move one's head or neck in certain ways to get food down (e.g., jerking head backward)
5. Laborious chewing, repetitive swallowing
6. Coughing and/or choking during or after meals
Impaired functions associated with dysphagia and aspiration
1. Mumbled speech; wet, hoarse voice; gurgly voice during or after eating or drinking
2. Drooling, not able to keep bite/sip in mouth; pooling and pocketing of food in mouth
3. Frequent throat clearing during and immediately after meals
4. Noticeable increased amount of phlegm
Patient complaints and observations
1. "It is hard to swallow" or "the food won't go down"
2. "It feels like something is stuck in my throat" or "it hurts when I swallow"
3. "I have too much saliva"
4. "I have trouble breathing when I eat or right afterwards"
5. "When I eat, food comes out of my nose"

Can swallowing problems be treated in HD?
Yes. HD patients should be evaluated when signs and symptoms of dysphagia are observed. Swallow evaluations are done by a licensed speech language pathologist (SLP). The evaluation may involve a clinical swallowing test completed in one office visit of 30 minutes. Different swallowing positioning, techniques, and food consistencies can be tried during testing. If a person shows signs of aspiration (e.g., coughing, choking during or after a swallow) during the clinical swallowing testing, the SLP may request a video fluoroscopic swallowing study (VFSS) for further assessment. After evaluation, recommendations for appropriate diet consistency, effective positions, and swallowing exercises are given. Speech therapy visits may be useful for teaching compensatory or technical strategies for safe swallowing; and direct treatments for dysphagia. Goals are always to ensure safety with swallowing and adequate nutritional needs in the presence of HD.

How to find a speech language pathologist who is familiar with HD?

1. Use this link to find a clinically certified speech language pathologist near you **http://www.asha.org/profind/**
2. Call the Huntington's Disease Society of America at 212-242-1968

This article was written by:
Emily Wang, Ph.D., CCC-SLP, Speech Language Pathologist
Associate Professor, Department of Communication Disorders and Sciences
Rush University Medical Center

Jennifer G. Goldman, MD, MS, Associate Professor of Neurological Sciences, Section of Parkinson Disease and Movement Disorders, Rush University Medical Center and Director of the Rush University HDSA Center of Excellence, Chicago, IL.

Please pass this along to your support group members. The Illinois Chapter now has its own unique email address for contacting the chapter for problems, questions, and comments.
illinois@hdsavolunteer.org
While hdsailchapter@gmail.com is still active, it's no longer on our state webpage.

How to make a financial donation in memory of a loved one to HDSA

Many times when a loved one passes away, we're not sure how to make a financial donation in memory of your loved one to HDSA. If you go to our webpage, **http://www.hdsa.org/il**, you can click on the "Donate" button at the top of the page. You will be asked if it is a "general donation" or a "tribute or memorial" donation. Then follow the easy steps to make your donation by credit card. If you prefer to make a donation by check, please make it payable to**: Illinois Chapter-HDSA** and **enclose a note** stating that it is a donation in memory of the loved one. Checks can be mailed to:

Illinois Chapter-HDSA
P.O. Box 1883
Arlington Heights, IL 60006-1883

For your convenience, contact any board member if you need donation envelopes. We can send them directly to the funeral home handling the funeral details. Board members' phone numbers and email addresses are listed elsewhere in this newsletter.

Memorials and Tributes

In Tribute to Craig Srajer from Catherine Evers

In Memory of Sharon Mooney Wiese and Cathleen Wiese Ulbrich from Clarence Wiese

In Honor of Jennifer, Michael and Richie Bliven from Zachary Bliven

In Memory of Laura C Smith from Leonard & Lucy Kelley, Terry & Linette Brown, Cliff Armstrong, Russel & Carol Miller, Richard & Carolyn Smith, James & Barbara Ely, Richard & Mary Foulkes, Kaywin & Ann Lindsay, Brian & Janet Pavlons, Bonnie Grizzle, Warren & Violet Bates, Larry Hankins, Thomas & Shirley Boward, Carlton & Sandra Jenkins, Lawrence & Arlene Pennie, Fred & Marcia Giese, Charles Stewart, Brian & Nicholas Hitch, Gerald & Karen La Voie, Cooksville Grain Co

In Tribute to the Etchingham Family from Sheila M. Stephani, Michael R Mizwicki & Kristen Pugliani Mizwicki, The Children's Surgical Foundation, Inc, John & Lori Power

In Memory of Ralph Short from Lois Short

In Memory of Peter Gavras from Mildred Gavras

In Memory of John Allen Lynch from Mark & Patty Hansen, Jim & Janet Hicks, Phillip & Mary Ann Maton, Sharrie Eilers, Dick & Judy Lees, Johnnie Sanderfer, William Lynch, Community Banks of Shelby County, Doug & Terry Schafer, Sidney Lynch & Drew Matsumoto

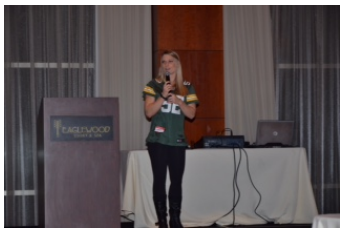
In Memory of Terry Bruno from Catherine Evers, Pat Cotton

"Score for HD" raises over $30,000!

By Marilyn & Barry Kahn

"Score for HD" was this year's theme for our annual winter fundraiser to celebrate Chicago sports teams in our fight against HD! It was held on Saturday, January 28, 2017 at Eaglewood Resort & Spa in Itasca, and was attended by over 150 people!

The evening began with a cocktail social hour, where everyone had a chance to socialize with 'old' and 'new' acquaintances. Barry then welcomed everyone and introduced the Illinois Chapter Board, as well as the sponsors and others who contributed to the evening's success. We were so pleased to be presented with a special gift from Holly Fraleigh in honor of our 10th year of chairing this winter event! Thank you!



The remainder of the Program consisted of a short welcome from Dr. Melany Danehy, from Rush University Medical Center and a special guest speaker, Shana (Martin) Verstegen, who spoke about her journey with HD and her inspirational words of living your life with HD. She has accomplished many things, from being the first female pole vaulter at the University of Wisconsin, to winning 6 lumberjack world championship titles, but her biggest challenge is with fundraising and raising awareness toward finding a cure for HD! Shana reminded everyone of the importance of raising funds to keep the positive momentum of finding a Cure for HD. This was realized by raising an additional $1,550 for "Cure HD" that evening! Thank you, Shana!

We would like to thank the following sponsors who helped make this event a success!

Olympic Sponsor	Fraleigh Foundation
Stanley Cup Sponsors	Marty & Elaine Jacobson STATS, LLC
Super Bowl Sponsors	Arlington Construction Services MCJ Jewelers & Goldbuyers The Ross and Ayres Charitable Fund

A successful event only happens because of the generosity, dedication and hard work of many people, so thank you to all who pitched in. A couple of special thank you's:

Raffle and Auction Committee	Holly Fraleigh Julie Bode Julie Campbell Katie Stevens

Our thanks to Larry Neiman of Centerpiece Productions for providing the centerpieces!!

Please continue to support our Chapter events in any way you can. It all helps in so many ways!

Fundraising...

It's true, fundraising is not always easy. We're all busy, time is hard to find, money is tight, you're not very organized, you don't like talking to strangers, your family and friends get tired of you asking for help…these are all the things we think when we hear the word ***fundraising***. Dispel those myths! Here are some easy ways to help raise the funds that so dearly help HD families, research and education.

- Donate a portion of your profits from your small business
- Donate money from a garage sale
- Collect pop cans from your neighborhood for a month (and save those pop tabs too!)
- Have a car wash or a dog wash…just need a hose, some soap and a sign (and kids can help too!)

Remember, you don't always have to think BIG! Every little bit counts. Donations can be made securely online by going to www.hdsa.org/il.

Book a Room: Registration for Convention does not ensure a room reservation at the Renaissance Schaumburg Convention Center Hotel. You must make your room reservation separately with the hotel by calling 1-800-468-3571. (Reference group: **Huntington's or HDSA**) The rate at the Renaissance Schaumburg Convention Center Hotel is: $134 plus taxes. Book by May 29, 2017 (while supplies last) in order to receive this special discounted rate. Renaissance Schaumburg Convention Center Hotel, 1551 N. Thoreau Drive, Schaumburg, IL 60173. Reservations: 1-800-468-3571 Website: www.hdsa.org/conventionhotel.

Travel: We are pleased to offer you discounted airfare through United Airlines. You may book online at www.united.com and enter offer code ZY53458549 in the offer code box when searching for your flights. Discount valid on travel dates between 6/16/2017 to 6/29/2017 to O'Hare Airport.

Registration Pricing: (Ticket Cutoff May 12, 2017)

Ticket	Quantity Left	Price Each
Early Bird Adult (when registering a single adult)	Available	$190.00
Early Bird Family (2 or more adults) $155 rate is per person . In quantity box enter total number of adults.	Available	$155.00
Early Bird National Youth Alliance (29 Years and Younger)	Available	$115.00
Early Bird Non-NYA (Children 18 and under)	Available	$115.00
Early Bird Convention Gala Only	Available	$75.00
Early Bird Friday Day Pass- (Does not include Convention Gala)	Available	$120.00
Early Bird Saturday Day Pass (Does not include Convention Gala)	Available	$120.00

Renaissance Schaumburg Convention Center Hotel
1551 N. Thoreau Dr., Schaumburg, Illinois 60173
Phone: +1 847 303 4100

Parking at Hotel:
Complimentary on-site parking
Valet parking fee: $17 USD Daily
Valet parking includes in/out privileges

Don't miss your opportunity to apply for the Illinois Resident Scholarship to attend the 32nd Annual HDSA Convention

This special scholarship, open to **Illinois Residents**, is made possible thanks to the generous support of Lundbeck.

Cut/paste the link below into your browser for the application (*application deadline is 4/19/17*): http://hdsa.org/wp-content/uploads/2015/01/HDSA-Convention-Scholarship-Illinois.pdf

If you have any questions please contact Deb Boyd at dboyd@hdsa.org. See you in Schaumburg!

Weeding out the truth: can cannabis improve Huntington's?

What can individual experiences with cannabis tell us about Huntington's disease?

By Dr. Michael Flower on February 24, 2017Edited by Dr. Ed Wild

Cannabis, or medical marijuana, has been touted as a treatment for lots of conditions, and Huntington's disease is no exception. Whenever it hits the news there's a lot of interest, and recently cannabis found the spotlight again with videos claiming it can reverse the nerve cell damage in Huntington's disease. These are extraordinary assertions that deserve to be explored.

What is cannabis?

It's a plant, originally from Asia and India, that's been known for thousands of years to have effects on the human brain. Many cultures have used it medically and recreationally. It's psychoactive, which means that when taken – for example, by smoking its leaves – it alters the way our mind perceives things, characteristically inducing relaxation and euphoria, but it can also cause anxiety and paranoia.

Whether in synthetic or natural form, there is no proper scientific evidence that cannabis helps Huntington's disease patients

It wasn't until the 1940s that we discovered the active ingredients, which are oily chemicals called **cannabinoids**. Other plants make cannabinoids too, including some herbal teas, truffles and even cocoa.

How it works

In the late 1980s, we discovered that humans have tiny sensors, called receptors, for these cannabinoids on the surface of our cells. There are two main types of receptor – CB1 and CB2. Most **CB1** receptors are in the brain and spinal cord. It's these ones that are thought to produce the psychoactive effects. The receptors affect how active our nerve cells are, for example controlling the amount of pain a person feels. In contrast, **CB2** receptors are found on immune cells that circulate in our blood, and activating them can have an anti-inflammatory effect. Normally there are very few CB2 receptors in the brain, and those that are there, are found on immune cells.

Having found sensors for cannabinoids in the human body, the logical conclusion was that we might also naturally make cannabinoids. And indeed, the first of these was found in the early 1990s, followed shortly after by several more. Nerve cells use them as a way of regulating their own activity level. Normally one nerve cell passes information to another by sending a **neurotransmitter** chemical. Cannabinoids are a way for the second nerve cell to pass a message back to first, telling it to calm down.

'Cannabinoid' is the name we call any chemical that activates cannabinoid receptors. The ones that plants make are called **phytocannabinoids**. Phyto- comes from the Greek for plant. The ones our own bodies make are called **endocannabinoids**, derived from the Greek for 'within'. It's also possible to manufacture chemicals that activate these receptors, and we call these **synthetic cannabinoids**.

Different cannabinoids have stronger or weaker effects at each receptor, so they can have varied effects on our bodies. Once in the body, they are eventually broken down by the liver. Some are also stored in fatty tissues, along with their breakdown products from the liver, and these can be detected for several weeks afterwards in blood 'drug tests'.

"Through proper clinical trials, researchers can prove whether a potential treatment is both effective and safe. This is the standard that all other medicines are held to, and it shouldn't be any different for cannabinoids. *"*

The cannabis plant contains over 100 different cannabinoids, but the most psychoactive is **tetrahydrocannabinol**, otherwise known as **THC**, which potently activates CB1 receptors. The other main cannabinoid, **cannabidiol (CBD)**, isn't psychoactive. In fact, it reduces the activation of both CB1 and 2 receptors.

Cannabinoids can be extracted from plants and purified. Different strains of the plant are bred for different purposes, and each contains a different proportion of the cannabinoids. Hemp, for example, is a sturdy fibre that's been used in paper and clothes and is low in the psychoactive chemical THC. Cannabis plants used recreationally tend to have high THC. Cannabis is illegal in some places, while elsewhere it is legal for medicinal or recreational use. Scientific research is going on to see if it could benefit people with Huntington's disease.

Do cannabinoids improve Huntington's disease?

Scientists around the world have been studying their effects in Huntington's disease. Most work has been done in cells grown in the lab, or in animals bred to have the disease-causing gene. Some research suggests that CB1-targeting chemicals may protect cells against toxins. In the brains of Huntington's mice, CB1 receptor levels have been found to be reduced and CB2 levels are increased. Loss of CB1 receptors may be involved in some symptoms of the disease, because Huntington's mice that lack the CB1 receptor tend to have worse movement control. The increase in CB2 receptors may be one of the body's ways of dealing with HD. This theory is strengthened

by research showing that mice treated with CB2-targeting chemicals have less nerve cell death – possibly because this calms down the immune system in the brain.

These results in cells and animals are encouraging, but humans are a lot more complex. Bitter experience has taught us that very often results can be inconsistent, or even completely different, when therapies are scaled up for use in humans. Unfortunately, no cannabinoids have translated into effective treatments in people with Huntington's disease yet. Several clinical trials with cannabis extracts or synthetic cannabinoids **didn't** reduce the abnormal movements, like chorea, or affect the course of the disease.

But a video on the internet shows cannabis works for HD!

Proper clinical trials, with 'blinded' and 'placebo-controlled' designs, are how to find out whether a drug really works.

Searching the internet, you'll find several videos and news stories suggesting people's Huntington's disease has been reversed by cannabis. We're very pleased that these individual patients have found something that works for them.

But unfortunately, **these anecdotes aren't scientific evidence**. Based on these brief snapshots, it's impossible to tell whether they have actually improved overall. Huntington's symptoms naturally vary, and are influenced by many factors, like sleep and infections. We don't know about these patients' genetic mutations, the stage of their disease or what other medications they're taking. We also have to bear in mind the powerful **placebo effect** of therapies like this, where a significant proportion of people are known to improve because they believe strongly in a treatment, rather than because of any properties of the drug itself. There's also a strong bias in mainstream and social media towards the publication of success stories like these, but nobody writes about all the people who tried cannabis and didn't improve, or felt worse afterwards.

Through proper clinical trials, researchers can prove whether a potential treatment is both effective and safe. This is the standard that all other medicines are held to, and it shouldn't be any different for cannabinoids.

Claims that there's a solid body of evidence supporting the use of cannabinoids in Huntington's disease is highly misleading, and there's certainly no evidence that they can cure or reverse the disease. However, it's also worth remembering that there are several exciting potential drugs being trialed around the world right now that hold great promise. Cannabinoids are just a small part of the big picture, and real progress is being made in understanding and treating Huntington's disease.

But where's the harm in it?

There currently aren't any treatments capable of curing Huntington's disease, so some might think sufferers have nothing to lose from trying alternative therapies. However, there are risks.

"Right now there is no evidence to show that cannabinoids work in Huntington's disease, for symptoms or slowing down progression.*"*

The natural world is chock-full of potential treatments for all manner of diseases. Aspirin, penicillin and even some cancer drugs were purified from natural sources. But even drugs from natural sources can be harmful. Recreational cannabis use is known to carry a risk of psychosis, and medical cannabinoids can also cause sedation, anxiety, depression, dizziness, and nausea. They can interact with other medicines like antihistamines and antidepressants. Trials in multiple sclerosis have also raised a possible risk of epilepsy. These aren't reasons to stop studying cannabinoids as a potential therapy for Huntington's, but they do mean we should be very careful and ideally study them in properly monitored clinical trials.

Letting the smoke clear

Right now there is no evidence to show that cannabinoids work in Huntington's disease, for symptoms or slowing down progression. That doesn't negate anyone's personal experience, but it does mean that individual anecdotes or videos need to be interpreted with healthy caution – especially when the people making the claims are the people who stand to make profit from the 'cure'.

The research community hopes that cannabinoids will be shown to be effective and safe enough to be able to prescribe, but we don't have the evidence to make that decision yet. Whilst cannabinoid research is telling us a lot about the biology of Huntington's disease, it's certainly not the only avenue under investigation, and exciting trials in other treatments may change the playing field in the not-too-distant future. The best way to fight Huntington's disease is through rigorous scientific research to develop treatments that are effective, reliable and safe.

HDdennomore

EXCITING NEWS: May 18th in Vatican City, Italy, in the first ever Papal audience, Pope Francis will meet with people affected by Huntington's disease from South America. The purpose of the event is to raise awareness of Huntington's disease and the overwhelming challenges faced by the patients, families and caregivers affected by the disease. As part of the **HDdennomore** initiative (pronounced "Hidden No More"), the event aims to shine a light on and bring global attention to the HD community, and to mobilize action to improve the lives of those affected by HD.

HDdennomore and the event with Pope Francis is made possible by a global coalition of patient advocates, including Factor-H, the Huntington's Disease Society of America (HDSA), Elena Cattaneo (professor and lifetime senator) and Charles Sabine.
Visit **www.HDdennomore.com** for the latest information on this event.

News from Our Illinois Chapter Social Worker Emily Zivin, LCSW

Huntington's Disease Society of America
Tel: 630-443-9876 or E-mail: ezivin@hdsa.org

Mindfulness is defined as a mental state achieved by focusing one's awareness on the present moment. Mindfulness mediation is a practice that has shown to be a powerful tool in stress reduction. In general, it has proven to be effective in reducing anxiety, improving attention, memory and physical health. The practice of mindfulness has been shown to improve the daily lives of many individuals.

The basic components of mindfulness training include:

- *Non-judging*: Being an impartial witness to your experience
- *Patience*: Understanding that growth happens on its own time
- *Beginner's mind*: A mind that is willing to see everything for the first time
- *Trust*: A basic trust in yourself, feelings and experience
- *Non-striving*: The only goal is to just be you
- *Acceptance*: See things as they actually are in the present
- *Letting go*: Letting go of the impulse to hold on to/or push away experiences

Learning mindfulness tools can help with stress reduction when obstacles occur. It can help an individual maintain an open mind and remain calm in difficult situations. Mindfulness practice can be formal classes, online/apps or just being with a loved one. The simple act of taking a walk is a way to connect to yourself or one another.

Mindful training is an important practice that can help those living with HD and their loved ones. Learning to relax is a skill that is difficult to maintain. Letting got off reactions that have not worked in the past and opening yourself up to new situations, can be beneficial to everyone. That is the best form of mindfulness.

Mindfulness resources:
Free mindfulness apps: **http://www.mindful.org/free-mindfulness-apps-worthy-of-your-attention/**
Books: http://www.mindfultips.com/top-10-books-for-learning-mindfulness/

CARING and COPING

The **2017 HDSA Illinois State Conference** was a success!

This year the conference, *Caring: Empowerment for Managing HD* was held in downtown Chicago at the Northwestern Memorial Hospital Feinberg Pavilion. Northwestern Memorial Hospital was just named a Center of Excellence making this the perfect welcome!

Approximately 150 people were in attendance. Many topics were covered including Technology for Caregiving, helpful information on Physical Therapy and Nutrition in all stages of HD, genetics and reproduction options, research and clinical trials update, and even a diversified panel of HD caregivers sharing their perspectives and challenges. Many thanks to all who contributed and attended! As always we are interested in any feedback you may have or suggestions for topics for next year - send us an email at holly.fraleigh@gmail.com.

Our Genetic Info is NOT Up For Sale

Let Your Representatives know that we can't accept a bill like HR 1313 passing through the House On March 2, 2017 Rep. Virginia Foxx introduced the Preserving Employee Wellness Act (H.R. 1313) which, supporters of the legislation claim, provides needed flexibility for Employee Wellness plans. However, the bill also includes provisions that endanger our privacy and right to keep our genetic information out of the hands of our employers or even third parties. The HD community worked hard to pass the Genetic Information and Nondiscrimination Act (GINA) in 2008, and we won't allow anything to compromise those protections. As a community, we can't accept a bill that opens the doors to employers requesting genetic testing to participate in wellness plans while allowing harsh penalties for opting out. Let your Representative know today that compromising the protection of our genetic information is unacceptable, and ask them to oppose HR 1313! Access the link below to send your email:
http://cqrcengage.com/hdsa/app/onestep-write-a-letter?0&engagementId=314913

13TH ANNUAL - Team Hope Walk

SUNDAY, MAY 21, 2017 ~ NAPERVILLE RIVERWALK *(RAIN OR SHINE)*

REGISTRATION: 9:30AM ~ WALK BEGINS: 10:30AM

If you have any questions, please contact Dave Hodgson at 815-498-6092 or email at spiketdog@softhome.net.

The Illinois Chapter invites everyone to join us for the 13th Annual Team Hope Walk which will be held on Sunday, May 21, 2017, at the beautiful Grand Pavilion of the Naperville Riverwalk in Naperville, IL. To register, please visit our webpage at: **http://www.hdsa.org/thwnaperville**. As in past years, registration will begin at 9:30 AM and we will walk at 10:30 A.M. After the Walk, stick around for the now famous HOT DOG LUNCH! Also, as in past years, The Carnival Bag Raffle promises bigger auction items than ever. Additionally, we will have some surprises for the kids and adults. Pre-registration through the above link guarantees you the correct t-shirt size. Pre-registration is $20 and will save you $5 over walk-in registration fee of $25 the day of the event. We can only guarantee the first 400 who pre-register will have a correctly sized t-shirt. We anticipate that the 2017 Team Hope Walk will surpass the record setting 2016 Team Hope Walk, the biggest walk in HDSA history! Did you know that the 12 annual Team Hope Walks have grossed nearly $700,000.00? Let's set another record this year! If you have any questions, please contact Dave Hodgson by phone at 815-498-6092 or by email at spiketdog@softhome.net. We look forward to seeing you there!

The Riverwalk is very people friendly with park benches, along the way. It is wheelchair, wagon, and stroller friendly! Dogs are welcomed as long as they are on a leash. Please be sure to bring your lawn chairs and plenty of your own non-alcoholic drinks for everyone walking in your group. Don't forget water for your dog too!

Fundraising

Team Hope Walks aim to raise as much money possible in the local community to support the mission and services of the Huntington's Disease Society of America. There are many different fundraising strategies you may use to have a successful fundraising campaign, and HDSA suggests you use all of them! Please go to the walk website and download the Team Hope Walk Participant Packet and check out the Team Hope website's Fundraising Tips & Tools (including some fundraising webinars!) and Participant Resources sections.

Sponsorship

We invite all local companies and small businesses to sponsor this Team Hope Walk. We depend on the generosity of sponsors, and by sponsoring a walk, your company will be supporting a great cause as well as engaging in an exciting marketing opportunity within the local community. If your company or a company you know is interested in sponsoring the walk, please email teamhope@hdsa.org!

Proceeds support HDSA's fight to improve the lives of people affected by HD and their families. As in past Walks, memorial and business signs are available for a $100 donation and will be displayed near the Walk. We hope all of our families affected by HD will join us and make this year's Walk our most successful one!

NATIONAL SPONSORS

TEVA Neuroscience

Asclephius Healthcare Resource

This year's challenge: Have 10 FRIENDS sponsor you!

PLEDGE SHEET

Collect pledges from family members, friends, co-workers, neighbors, church members, teachers or anyone who would like to join you in your personal fight against HD. Please place pledge sheet and all collected donations in a sealed envelope with your name and total collected on the outside of the envelope. Please turn in your pledges on Walk Day.

Huntington's Disease Society of America
Illinois CHAPTER
Family is *everything*

13th ANNUAL TEAM HOPE WALK

	NAME	ADDRESS	AMOUNT	
1.				Good Start
2.				
3.				
4.				
5.				Getting Closer
6.				
7.				
8.				
9.				
10.				You Did It!
11.				
12.				
13.				
14.				Keep Going!
15.				
16.				

Name: _____
Address: _____
City: _____ St: _____ Zip: _____

Waiver: I hereby waive all claims against the Huntington's Disease Society of America, sponsors or any personnel for any injury I might suffer from this event. I attest that I am physically fit and prepared for this. I grant full permission for organizers to use photographs of me to promote this event.

Signature: _____

SUPPORT groups

Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
2nd Sunday of **even months** TIME: 2:00 to 4:00pm LOCATION: St. Joseph Medical Center, Bus. Conf. Center – Room 2, 2200 E. Washington Street, Bloomington, IL	**2017 Meetings:** 2/12, 4/9, 6/11, 8/13, 10/8 (No meeting in Dec.)	Dave or Susie Hodgson (815) 498-6092 spiketdog@softhome.net
GENEVA		
3rd or 4th Sunday of **odd numbered months** (see dates in next column) TIME: 2:00 to 3:30pm LOCATION: Cadence Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot) * Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome.	Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left. **2017 Meetings:** 1/29, 3/26, 5/28, 7/23, 9/17, 11/12	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
2nd Monday of **every month** TIME: 7:00 – 8:30pm LOCATION: Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville, IL	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403 marilynkahn1@gmail.com
ROCKFORD		
2nd Sunday of **every month** TIME: 2:00 – 4:00pm LOCATION: OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL * Use the main entrance - second one back from the parking lot entrance. As you enter the building you'll see a counter staffed by volunteers. Turn right, before you reach the counter. The St. Anthony Room is straight ahead.	Open to people with HD, family members, caregivers, and interested professionals.	Cheryl Sutton (815) 262-4889 cjs@hdsupportrockford.org
SOUTH SUBURBAN		
2nd Tuesday of **odd months** TIME: 7:00 – 8:30pm LOCATION: Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	**2017 Meetings:** 1/10, 3/14, 5/9, 7/11, 9/12, 11/14	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
4th Tuesday of **even months** TIME: 7:00 to 8:30pm LOCATION: Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4th Floor, Suite 04527, Chicago, IL * Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets. From the 4th floor, follow the signs to the Tower.	Valet parking is available in front of 1620 W. Harrison. Parking at both of these venues will be validated in full.	Dr. Steve Clingerman (847) 778-2881 sclingerman@cookcountyhhsorg Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD
CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL		
Meeting Date: 1/28/2017, TIME: 10:00 - 11:30am Northwestern Memorial Hospital Feinberg Pavilion Room: Feinberg NM Acd-2-715 **Meeting Date: 3/18/2017**, TIME: 10:00 - 11:30am Northwestern Memorial Hospital Feinberg Pavilion Room: Feinberg NM Acd-2-715 **Meeting Date: 5/13/2017**, TIME: 10:00 - 11:30am Northwestern Memorial Hospital Galter Pavilion Room: Galter 8-234 675 North St. Clair	For At Risk (non-symptomatic) patients and family members.	Emily Zivin (630) 443-9876 ezivin@hdsa.org **Parking Passes Available**
MUNSTER, INDIANA		
2nd Tuesday of **even months** TIME: 7:00 – 8:30pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	**2017 Meetings:** 2/14, 4/11, 6/13, 8/8, 10/10, 12/12	Cindy Rogers (219) 836-2369 clrogers111@comcast.net

Sadie Foster, M.A., L.C.P.C., has a telephone Information & support call service for HD families. This call is held the fourth Sunday of every month at 7pm. To participate dial 630-300-6276 and when asked, enter code 702087#. You do not need to identify yourself on the call.

For additional support you may call:

Sadie Foster, MA, LCPC, at the College of Medicine Huntington's Disease Clinic Tel: 815-271-7101 or E-mail: sadie@sfoster.com

Sarah Mitchell, Rush University Medical Center Social Worker
Tel: 312-942-6445 or E-mail: sarah_mitchell@rush.edu

SAVE THIS DATE!

May 21, 2017	HDSA IL Chapter Team Hope Walk for a Cure – Naperville, IL
June 22-24, 2017	HDSA 32nd Annual Convention – Schaumburg, IL

https://hdsa.org/il

SPRING 2017